



Defining New Metrics for HIV Prevention, Treatment and Stigma

COMMUNITY DATA MATTERS

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International Treatment Preparedness Coalition (ITPC)

90-90-90 Targets Update

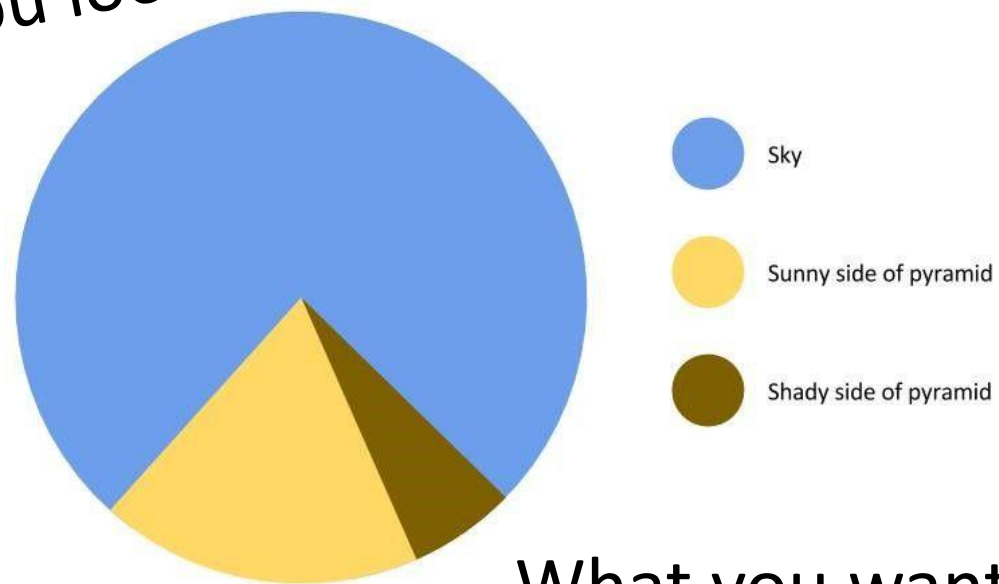
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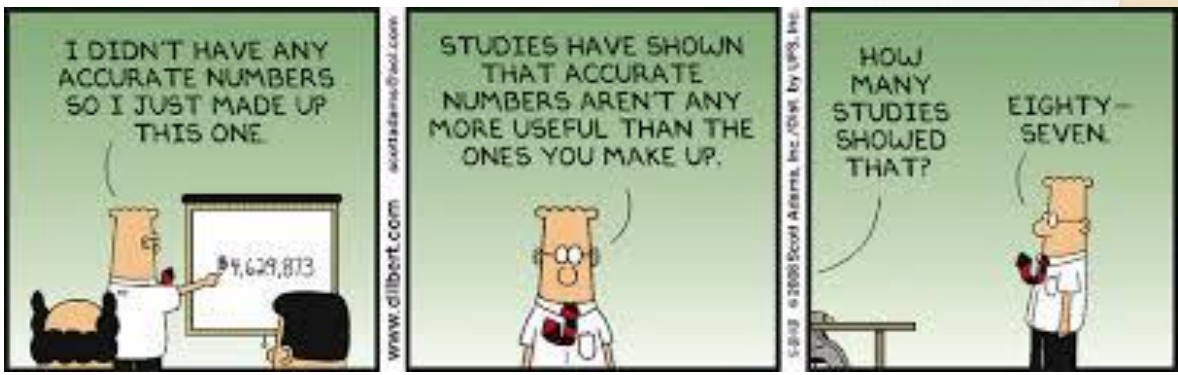
How you look at it



What you want it to say

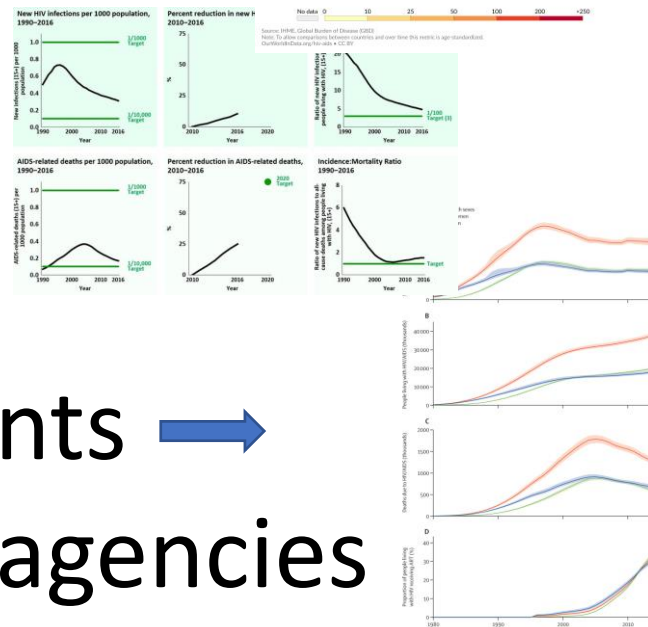
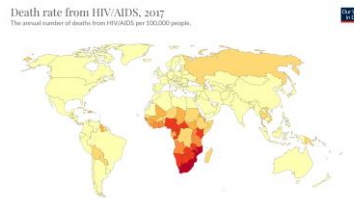


What you want it to say



Metrics and Measuring

- ✓ Numbers and %
- ✓ Coverage
- ✓ Academic institutions
- ✓ Governments → Normative agencies



- ✗ Quality
- ✗ Qualitative data
- ✗ Community Lens –
 - Research
 - Monitoring
 - Insights

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SNAPSHOT OF ITPC's EXPERIENCE

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Community-Led Data: Research, Monitoring and Advocacy

When Communities Lead...

- **Ownership of the Process** – communities have a vested interest in the outcomes; data collected does not “vanish” as it often does with other traditional researchers. Community systems are also strengthened in the process – staff develop skills in data management, M&E and advocacy, orgs. build program track record etc. (CSS).
- **Appropriate & Responsive Interventions** – solutions are closer to the issues; community-led interventions can generate more valuable (honest) insights to address their pressing needs.
- **Action- & Accountability-focused Results** – data collection & analysis is for a purpose; it is directly linked to advocacy or other targeted action to improve quality and service delivery and hold duty-bearers to account.

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EXAMPLES OF WHAT WE COLLECT?

QUANTITATIVE INDICATORS

- # knowing HIV status
- # of HIV co-infections care and treatment
- Cost of services
- Access to reproductive & family planning services
- # of people tested, initiated on ART, virally suppressed (sub-populations)
- Length and frequency of stockouts of ARVs, lab reagents for VL tests, HIV tests
- # of days to get VL test results

QUALITATIVE INDICATORS

- Where do you prefer to get services and why?
- Reasons for not going for an HIV test?
- Reasons for not accessing ARVs?
- How would you rate the quality of service at the facility?
- How was your interaction with HCP?
- Reasons for not accessing a VL test?
- Reasons for stockouts of medicines?
- What barriers face accessing services?

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COMMUNITY TREATMENT OBSERVATORIES



Regional Community Treatment Observatory (RCTO)

- 11 countries in West Africa (Benin, Côte d'Ivoire, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Mali, Senegal, Sierra Leone and Togo)
- Quantitative (monthly) and qualitative (quarterly) data collection at health facilities
- Community data collectors (PLHIV networks & KPs)

Southern Africa Community Treatment Observatory (saCTO)

- 3 countries (Malawi, Zambia and Zimbabwe)
- Quantitative (monthly) and qualitative (quarterly) data collection at health facilities
- Community data collectors (PLHIV networks & KPs)
- Paper and mobile data collection

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The Power of **BIG DATA** in the Hands of Activated Communities

<http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>



11
Countries



631,863
HIV tests performed



2
Years of monitoring



105,435
People on ART



84
Data collectors



81,380
VL tests performed



125
Health facilities



1501
Interviews



98,651
Young people reached



1781
Quantitative reports



143
Focus groups



35,577
Key populations reached

A representative sample size for the entire West and Central African region (95% confidence interval).



KEY RESULTS of ITPC's Community-led Monitoring

<http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>

Fig 1. Frequency of Recorded ART Stock-outs at RCTO-WA Monitored Facilities

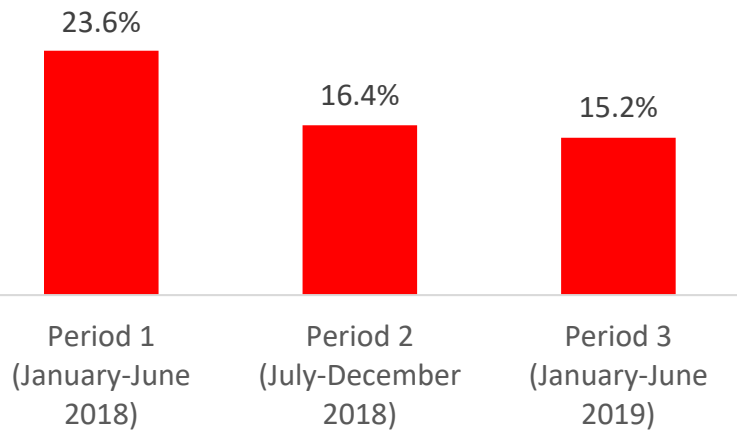


Fig 2. Frequency of Recorded VL Lab Supply Stock-outs at RCTO-WA Monitored Facilities

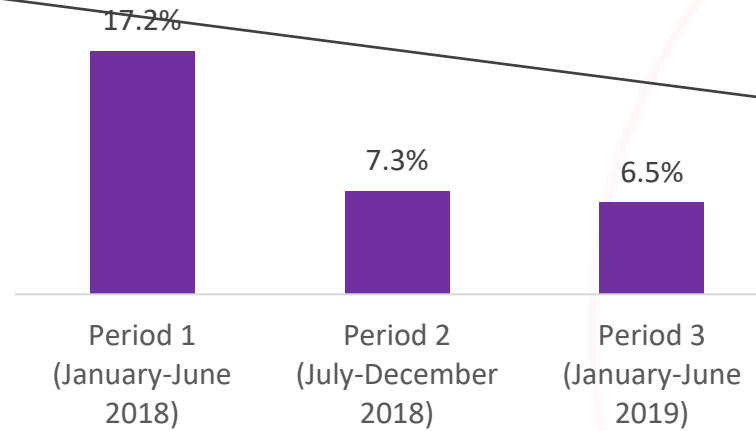


Fig 3. Average Length (days) of ART Stock-outs at RCTO-WA Monitoring Facilities in Côte d'Ivoire

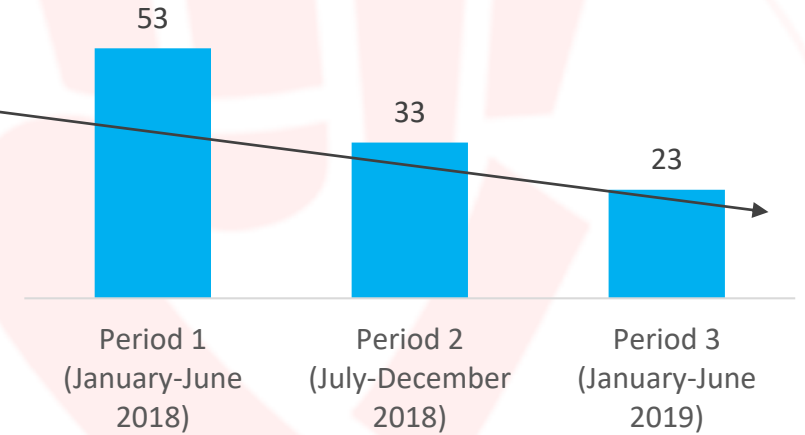


Fig 4. Average Quality of Care Rating (out of 5) at RCTO-WA Monitored Health Facilities

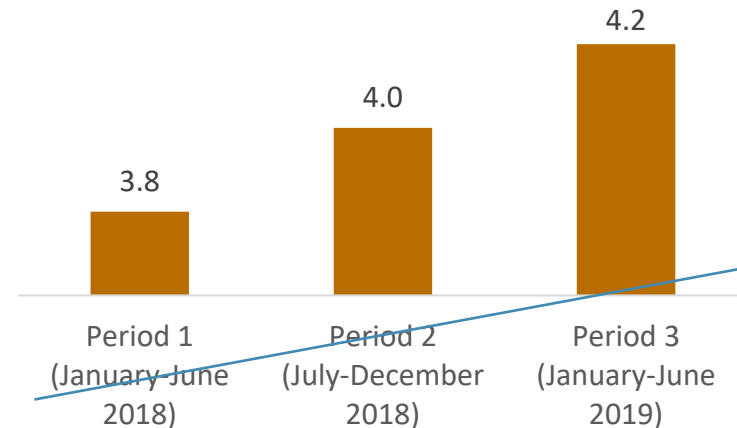


Fig 5. Viral Load Tests Performed at RCTO-WA Monitored Health Facilities

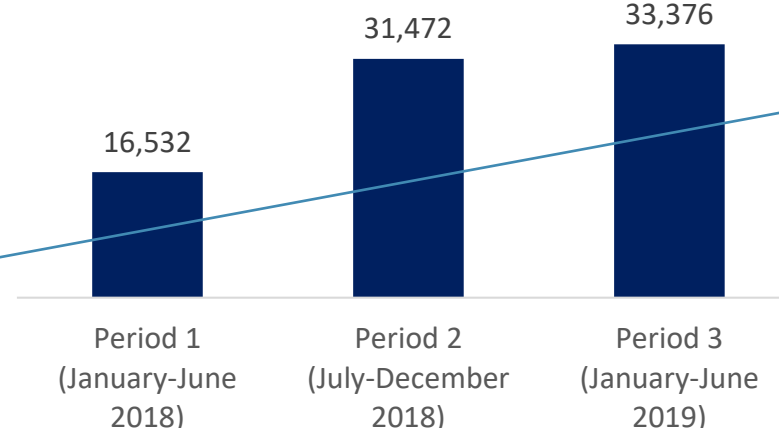
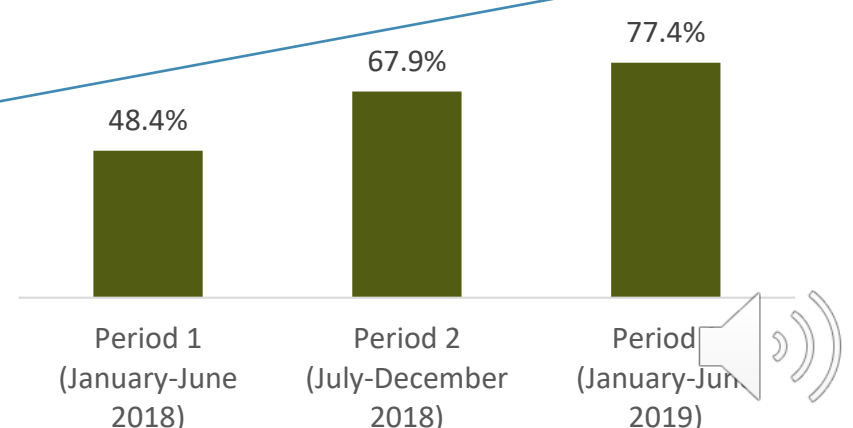


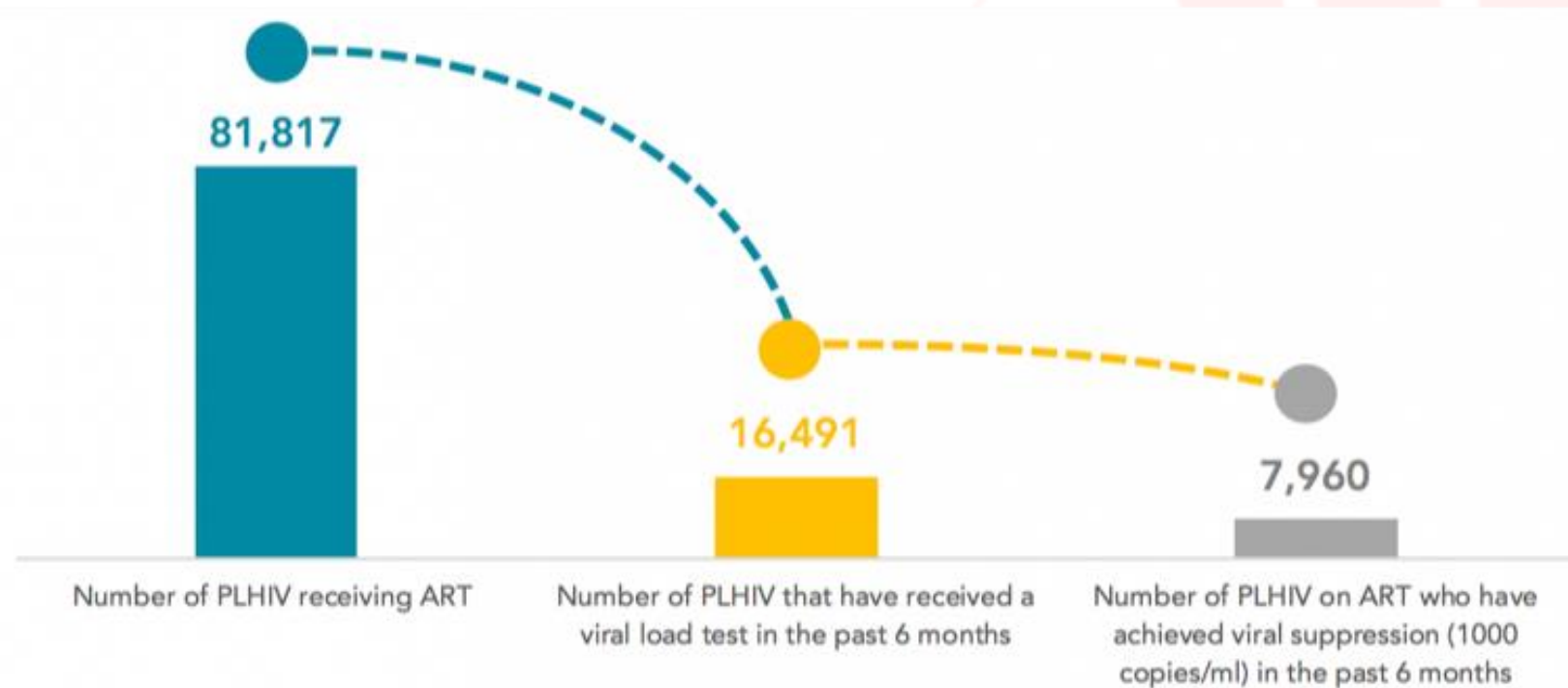
Fig 6. Rate of Viral Load Suppression at RCTO-WA Monitored Health Facilities



Access to Viral Load Testing Services and Viral Load Suppression Data at RCTO-WA monitored Health Facilities (as of June 2018)

ITPC Regional Community Treatment Observatory – 11 West African Countries

<http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>

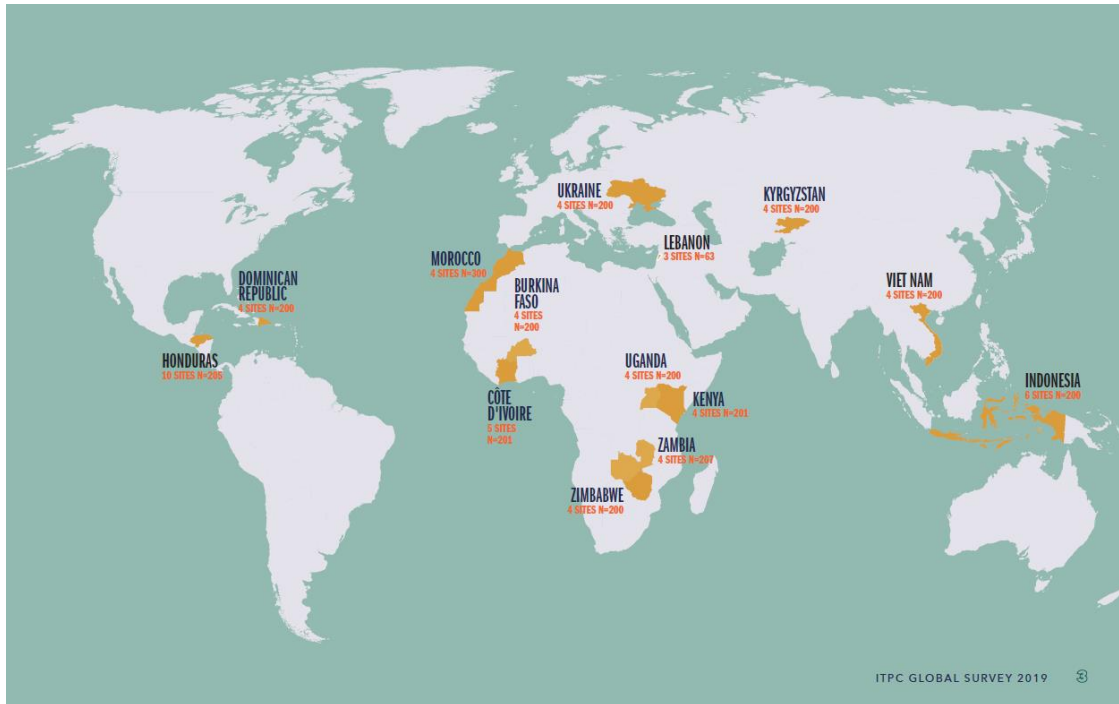


Of those who received a viral load test, less than half (48%) were virally suppressed - far lower than the UNAIDS estimate of 73%.

To what extent can community data challenge academic data?



COMMUNITY-LED RESEARCH ON TREATMENT ACCESS



Global Survey on Access to and Quality of HIV Care & Treatment

- 2777 total respondents
- 14 LMIC countries, across 7 regions
- Quantitative data collection with PLHIV at health facilities
- Qualitative data with KPs, healthcare workers and policy-makers
- Community data collectors

Missing the Target

- Access to HIV services among PWUD (Pakistan & Kyrgyzstan)
- Quantitative data collection with PWID living with HIV
- Qualitative data collection with civil society actors, healthcare workers and other key stakeholders

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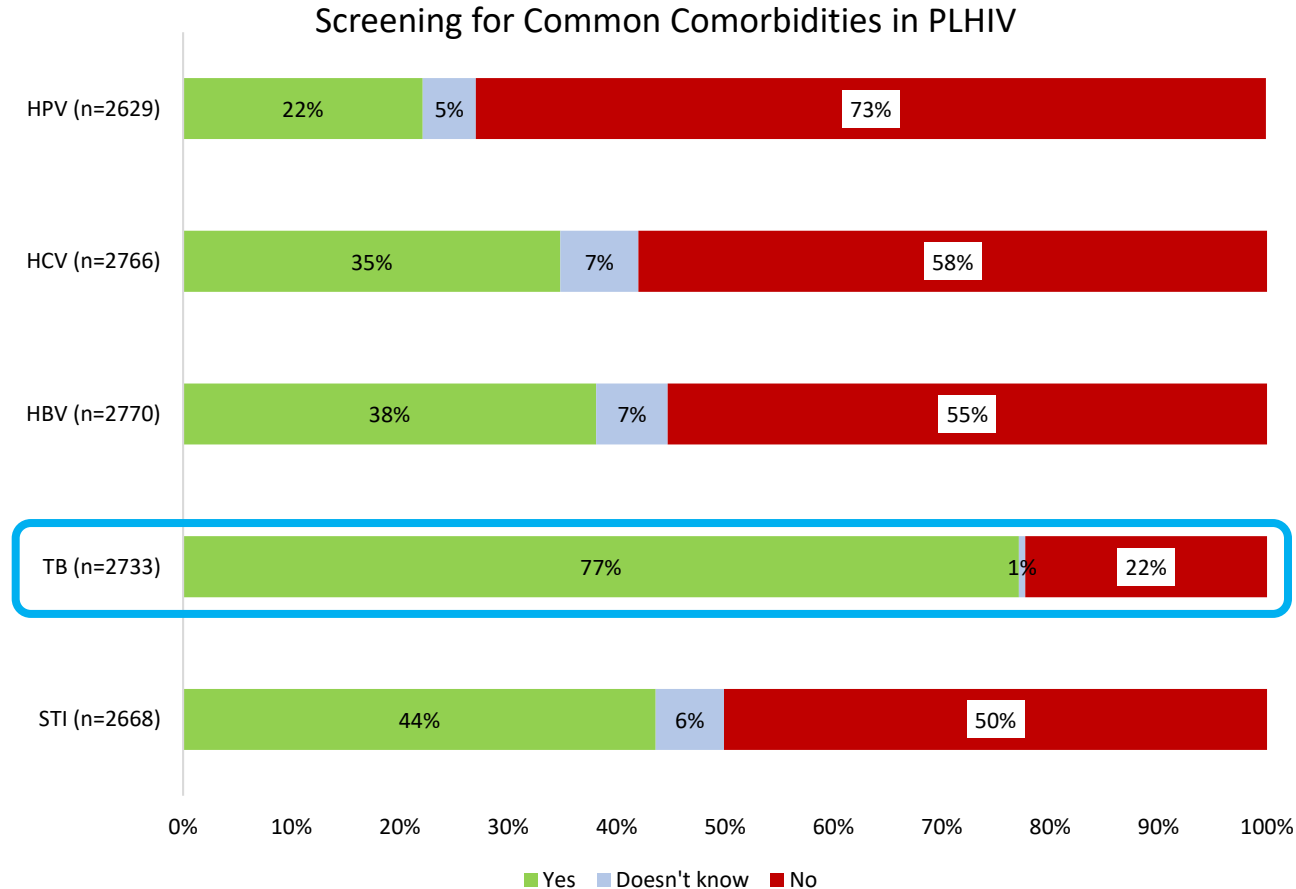
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Many ART Sites do not have the capacity to screen for Comorbidities

“Assessing Access to Quality HIV/AIDS Treatment: Achievements and Remaining Challenges” ITPC Global Survey 2017-2018 (7 Regions, 14 countries)

<https://itpcglobal.org/wp-content/uploads/2019/12/ITPC-Global-Survey-on-Access-to-and-Quality-of-HIV-Treatment-and-Care-December-2019.pdf>



- 26.1% of survey respondents reported that **testing for comorbidities was unavailable at their healthcare site**, forcing them to travel to a different health centre, where they frequently experienced stigma and discrimination from healthcare workers who did not provide to HIV care.
- WHO recommends that **all people living with HIV be tested for TB**. Only 77.1% participants reported being asked about TB symptoms / offered a test.
- Roughly a **third** of survey respondents were screened for common comorbidities, such as hepatitis B and C virus (HBV, HCV); an **even smaller** proportion were screened for **HPV, cryptococcal disease and cardiovascular disease**.

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Stigma remains a Pervasive and Deadly Barrier

“Assessing Access to Quality HIV/AIDS Treatment: Achievements and Remaining Challenges” ITPC Global Survey 2017-2018

<https://itpcglobal.org/wp-content/uploads/2019/12/ITPC-Global-Survey-on-Access-to-and-Quality-of-HIV-Treatment-and-Care-December-2019.pdf>

- Roughly **two thirds** of all respondents (64.6%) **experienced** an episode of **anticipated stigma** in the previous 12 months:
 - 20.7% reported avoiding social gatherings because of HIV status
 - 23.9% had not disclosed their status to any family member
- **More than a third** of respondents (37.8%) experienced an **act of stigma** in the previous year:
 - Most commonly being the subject of gossip (28.3%) and harassment (14.9%)
 - Loss of job were reported by 10.8% of people surveyed
 - Physical assaults by 6.2%

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Stigma remains a pervasive and deadly barrier, especially for Key Populations

<https://itpcglobal.org/wp-content/uploads/2019/12/ITPC-Global-Survey-on-Access-to-and-Quality-of-HIV-Treatment-and-Care-December-2019.pdf>

~2X

~60%

- Members of **key populations** were especially vulnerable to stigma from healthcare workers. For example, **MSM and SW** reported denial of health services significantly more than the general population (11.2% vs 5.9%).
- Internalized stigma among **56.7%** of respondents :
 - self-blame for HIV-status
 - decision not to have sex
 - decision not to have children

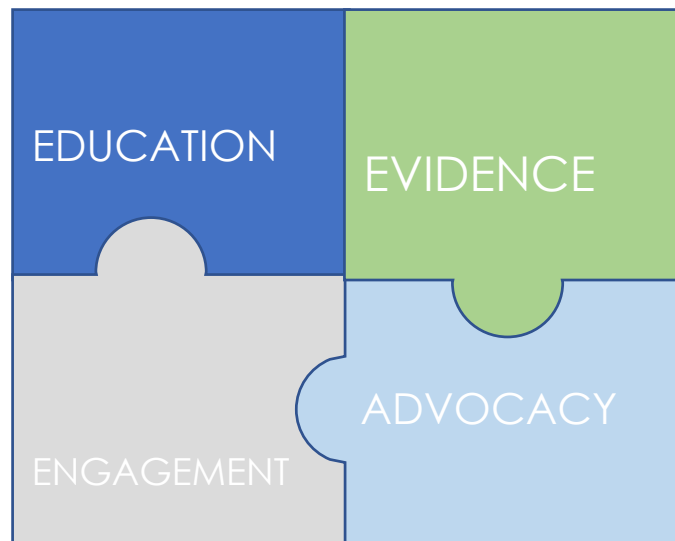
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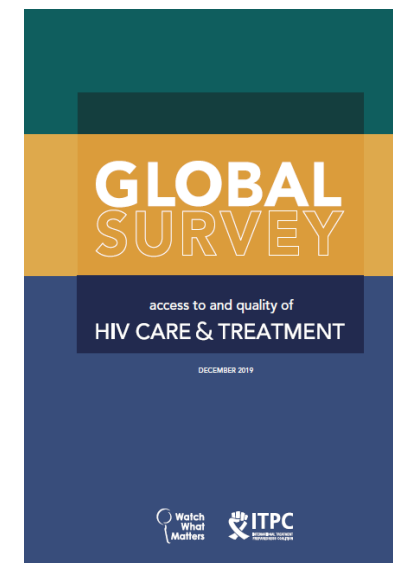
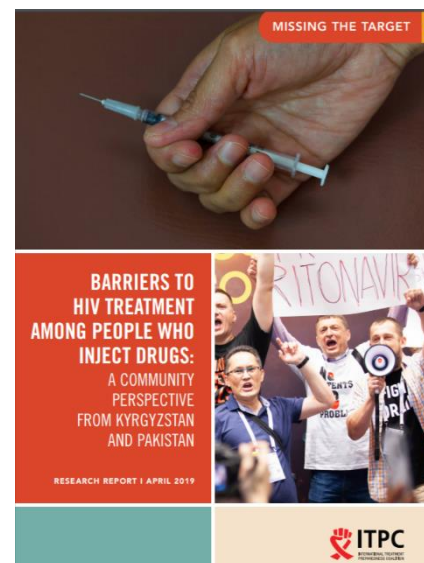
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Data ONLY Matters if **USED!**



- Collecting data **is not** the end-goal
- Insights equip communities to carry out evidence-based advocacy to address the gaps identified
- Resources below illustrate different ways in which data was used to **bring about change**



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Using Data to Alleviate Stockouts

The Critical Role of Advocacy

<http://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>

CTO SUCCESS STORY

BENIN

At the Bethesda Hospital in Cotonou, Benin, CTO host REBAP+ noticed that the site had not been supplied with lab reagents for more than 10 months. This meant that patients were not receiving critical treatment monitoring services, including viral load and CD4 count test. The CTO data on reagent stock outs was recorded in REBAP+'s report, for presentation to the CTO's Community Consultative Group (CCG). During this meeting of the CCG, the Deputy Coordinator of The National AIDS Control Program (Programme santé de lutte contre le Sida-PSLS) was confronted with REBAP+'s CTO data on reagent stock-outs. The CCG's function as a feedback mechanism for the CTO worked, and a solution was found. After the meeting, PSLS stocked Bethesda Hospital with reagents.



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Overview of Regional Advocacy Priorities



Advocacy Priorities for the RCTO-WA, set by the Regional Advisory Board in October 2018

By 2020, 90% of people living with HIV will know their status

- ▶ Expand the availability of **non-facility-based HIV testing options**, including community-led and community-based HTS
- ▶ Intensify HIV communication and awareness campaigns to **increase demand** for HTS
- ▶ Include objectives to promote and protect human rights of PLHIV and key populations in costed HIV strategic plans

By 2020, 90% of people living with HIV who know their status will be receiving sustained ART

- ▶ Improve communication along the **supply chain to prevent stock-outs** of antiretrovirals
- ▶ Enhance linkage to—and retention in—care and treatment, especially for key and vulnerable populations
- ▶ Strengthen community systems and responses to support the roll out of differentiated service delivery

By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression

- ▶ Increase funding to ensure the availability of **adequate viral load testing machines and laboratory supplies**
- ▶ Enhance **knowledge** among PLHIV and healthcare workers to increase demand for high quality viral load testing services
- ▶ Ensure effective treatment monitoring through acceptable turn-around times for viral load test results



Setting, *Chasing* and Reaching Targets

- Our ultimate measure of success = Healthy People
- Target setting is aspirational; as much of an art as it is a science
 - Models and assumptions; Not just #s
 - Structural, legal, socio-economic enabling factors
 - Granularity
- Estimates – population size, denominator issues



When we reach a target that is not well set, have we been successful?

- Often hear “we don’t have that data”; “it’s hard to get that kind of data”
- Not looking in the right place, or equipping the right groups to help to gather more of the necessary data

Community data can help to get more accurate estimates and ultimately inform better targets

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